

Managing the stigma: Exploring body image experiences and self-presentation among people with spinal cord injury

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Abstract

Using modified constructivist grounded theory, the purpose of this study was to explore body image experiences in people with spinal cord injury. Nine participants (five women, four men) varying in age (21–63 years), type of injury (C3–T7; complete and incomplete), and years post-injury (4–36 years) took part in semi-structured in-depth interviews. The following main categories were found: appearance, weight concerns, negative functional features, impact of others, body disconnection, hygiene and incontinence, and self-presentation. Findings have implications for the health and well-being of those living with a spinal cord injury.

Keywords

impression management, physical disability, qualitative, self-concept, well-being

Body image has been consistently agreed among scholars to be a multidimensional concept reflecting perceptual, cognitive, affective, and behavioral aspects (Cash and Pruzinsky, 2002; Thompson et al., 1999) and can be experienced positively or negatively (Cash and Smolak, 2011). Many negative body image experiences, particularly dissatisfaction, stem from the internalization of cultural ideals of appearance, particularly the westernized ideal body type. In Western culture, the ideal for a woman is White, thin, tall, young, and full breasted, with some visible muscle tone (Grogan, 2007). For men, the ideal is characterized by visible muscularity and large muscle mass, specifically in the arms, chest, and back (McCreary, 2011). Internalization of the ideal leads to the development of a cognitive schema that associates attaining the ideal with positive attributes such as happiness, social desirability, and social status (Stice, 1998). Embedded in the ideal for both men and women is the assumption of having an able body, implying anyone who has a physical disability can never attain the ideal. Most of the body image research has focused primarily on able-bodied female college and adolescent students' experiences, overlooking other samples (e.g. people with physical disabilities), which has been recognized as a limitation by seminal scholars in the field (e.g. Cash and Smolak, 2011).

One example of a physical disability that results in many physical changes to the body is a spinal cord injury. Spinal

cord injuries result from traumatic or nontraumatic damage to the vertebral column and/or spinal cord, resulting in impairment of motor and/or sensory function in the upper and lower extremities, trunk and pelvic regions, as well as autonomic impairments such as bladder or bowel function (Somers, 2010). Paraplegia is the result of a lesion at the level of the thoracic vertebra or lower in the lumbar and/or sacro-coccygeal regions. This type of lesion results in impairment of sensation and movement of the lower trunk and limbs. Tetraplegia (also known as quadriplegia) is the result of a lesion in the cervical vertebra. This type of lesion results in impairment of motor and/or sensory function in the upper and lower extremities, trunk, and pelvic region (Somers, 2010). These changes can, in turn, affect

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appearance (e.g. loss of abdominal muscle tone referred to as “quad belly”; Chau et al., 2008), functionality (e.g. changes in bladder or bowel function; Benevento and Sipski, 2002), and independence (e.g. Galvin, 2005) which can all influence body image. For instance, these changes to the body that result from a spinal cord injury may lead to more negative body image as individuals move further from the ideal. Research has found that those who have a spinal cord injury experience struggles with conformity to masculine gender roles (Burns et al., 2010), negative changes to sexual self-esteem and overall functionality (Potgieter and Khan, 2005). On the contrary, other research has found that people with spinal cord injury may also adjust positively by setting realistic goals, engaging in activities to feel useful, and feeling grateful (Dibb et al., 2014).

A handful of studies have explored body image experiences in people with physical disability. For example, a quantitative study by Moin et al. (2009) explored sexual satisfaction and body image in women with and without a physical disability (e.g. polio and spinal cord injury). They found that the women with physical disabilities had significantly poorer body image, sexual self-esteem, sexual satisfaction, and life satisfaction than the women without a physical disability. However, a study by Taleporos and McCabe (2002) found evidence suggesting that individuals with physical disabilities, including spinal cord injury, gradually adjust to their different bodies and increasingly accept their disabilities over time. Women with spinal cord injury in Bassett et al.’s (2009) study were slightly dissatisfied with their appearance and slightly satisfied with their function. Meanwhile, in another study by Bassett and Martin Ginis (2009) among men with spinal cord injury, the men indicated overall satisfaction with appearance and function. The authors proposed that this may have been due to the men lowering their appearance and functional standards following their injury by shifting value away from physical qualities or changing the reference group (to other men with spinal cord injury). However, no research has used an in-depth method to further explore these suggestions.

One concept closely related to body image is self-presentation (also known as impression management). Self-presentation refers to the process by which individuals engage in behaviors to control and monitor the impressions others form of them (Leary and Kowalski, 1990). These impressions are important because they can affect how people are perceived, treated, and evaluated by others. For example, there are many social rewards that accompany being viewed as physically attractive (i.e. meeting the cultural ideal) such as being perceived as more sociable, dominant, and intelligent (Leary, 1995).

Since physical disability has been found to negatively affect body image (e.g. body esteem) in people with acquired disabilities (e.g. spinal cord injury and multiple sclerosis; Pfaffenberger et al., 2011; Taleporos and McCabe, 2001), it may also affect self-presentation. For instance,

according to the Western ideal, people who have a spinal cord injury can never attain the ideal due to discernible aspects of their disability (e.g. use of a wheelchair). Particularly, when a physical disability is visible to the public eye, in an extreme case, people may regard them as deviant, flawed, or undesirable. People often react negatively to others’ flaws which can lead to negative inferences made about that person which then form into a stigma (Goffman, 1963). People not only evaluate stigmatized people unfavorably (e.g. unattractive, impotent, and asexual) but also behave differently toward them. Therefore, individuals who experience stigma may engage in a number of self-presentational tactics to minimize the impact of stigma. Although body image and self-presentation are two distinct constructs (body image being one’s own perception of the self and self-presentation being how people believe others may view the self), these constructs also overlap. For example, self-presentational concerns about appearance, perhaps induced by experiences of stigma, may create poorer body image. Furthermore, a negative body image may produce greater self-presentational concerns.

Body image experiences of people with spinal cord injury have been profoundly underrepresented in the literature. An acquired physical disability results in sudden changes to the body whereby adjustment occurs over time. For example, a spinal cord injury results in immediate physical impairments resulting in changes to appearance, functionality, and independence (e.g. Galvin, 2005). Learning about how individuals adjust to these changes may be essential information needed in hospital, rehabilitation, and exercise settings where adjustment to an injury may take place. Since there is evidence that individuals with spinal cord injury may adjust positively after their injury (Dibb et al., 2014), it might be important to explore the impact of stigma and negative body image to improving the well-being of individuals with spinal cord injury. A qualitative design may be needed to gather more in-depth accounts of body-related experiences in people with spinal cord injury. More specifically, the use of interviews has been shown to be an effective tool to create an environment for participants to share sensitive subject matter, such as embodiment, more openly (Liamputtong, 2009). This leads into the purpose of this study which was to broadly explore body-related experiences among people with spinal cord injury. The following theoretical question was explored: How do individuals with spinal cord injuries experience their bodies?

Method

Participants

Nine participants from southern Ontario who had a spinal cord injury were recruited for this study (five women, four men). We followed Patton’s (2002) recommendation of sample size. For example, approximately 7–10 participants

Table 1. Participant characteristics.

Participant	Age (years)	Gender	Age at injury (years)	Level of injury	AIS	Years post-injury	Height (in)	Weight (lb)	LTPA (minutes)
1. Rebecca	26	Female	21	T6	A	5	67	110	2/180
2. Samantha	32	Female	18	T1	A	14	69	140	3/60
3. Will	42	Male	38	C6	B	4	71	260	3/120
4. Lizzy	44	Female	34	T7	A	10	64	Unknown	0
5. Mark	21	Male	17	C7	B	4	68	190	3/30
6. Larry	48	Male	39	C3	D	9	71	180	1/120
7. Caroline	63	Female	27	C3	D	36	74	214	2/60
8. Star	36	Female	18	T3	A	18	64	121	2/60
9. Danny	35	Male	19	C5	C	16	69	215	0

AIS: American Spinal Injury Association Impairment Scale; LTPA: leisure time physical activity.

LTPA scores are based on self-reported number of days in the last 7 days participants took part in moderate to vigorous intensity leisure activity and amount of consecutive minutes they engaged in that activity. Recommendations are at least 20 minutes of moderate to vigorous activity for two times a week of aerobic and strength training activities.

is typical for a qualitative design where the goal is to ensure a sample size large enough to examine patterns between participants but to avoid having a sample that is too large with overwhelming amounts of data. Participants were included if they met the following criteria: 18 years or older, at least 12 months post-injury, and no history of a clinical eating disorder. Those who had a history of an eating disorder were not included due to the fact that they may have much more body image disturbance (Grogan, 2007). Participant characteristics can be found in Table 1. All names are presented as pseudonyms for anonymity purposes.

Study design

A modified constructivist grounded theory was employed for the current project. Grounded theory is “a systematic, yet flexible methodology for collecting and analyzing qualitative data to construct theories that are grounded in the data themselves” (Charmaz, 2006: 2). Historically, within grounded theory, researchers have maintained a position of “distant expert” (Charmaz, 2000: 513). Constructivist grounded theory challenges this basic tenet and asserts the importance of a multiplicity of perspectives and experiences. This enables the construction of theory that is richer and more reflexive of the context in which participants are situated. Given that little is known about body image in people with spinal cord injury, a constructivist approach is imperative to understand the subjective experiences of embodiment within this population. This study was one of the first to explore in-depth body-related experiences in people with spinal cord injury.

Materials

Leisure time physical activity questionnaire for people with spinal cord injury. A 15-minute telephone interview using

the leisure time physical activity questionnaire for people with spinal cord injury (LTPAQ-SCI; Martin Ginis et al., 2012) was administered to gather information regarding participants’ leisure time physical activity (LTPA) levels. This information was collected for purposes of the larger study; however, it was particularly valuable for rapport building to increase quality of the interview data.

Demographic information. A fact sheet was used to gather general self-reported sociodemographic information about the participants. These data included information about age, gender, weight (if known), height (if known), ethnicity, age at the time of injury, level of injury, and severity of injury using the American Spinal Injury Association Impairment Scale (AIS).

Data collection

Data were collected as part of a larger study investigating overall body image experiences and physical activity in people with spinal cord injury. Specifically, one published study explored positive body image experiences in people with spinal cord injury (Bailey et al., 2015). On university research ethics clearance, participants were recruited using purposive sampling procedures known as snowballing (Patton, 2002). The first participants were recruited through the exercise facility associated with the university and then interested participants were asked if they knew others who may be interested in participating who fit the inclusion criteria. Once participants displayed interest in the study, they were emailed a letter of invitation outlining details of the project, the LTPAQ-SCI, and the one-on-one interview guide (see Table 2). Then, participants were scheduled for a telephone and an in-person interview. Telephone interviews were completed first where participants provided verbal informed consent and lasted about 15 minutes.

Table 2. Interview questions.

1. Can you tell me a bit about how you view your body?
2. Tell me about how you first adjusted to your body after your injury?
3. Describe your experience during rehabilitation immediately after your injury with regard to how you felt about your body?
4. Will you talk about how you see and think about your body now?
 - (a) How about before your injury?
 - (b) How about acutely after your injury?
5. Overall, how do you feel about your body now?
 - (a) How about before your injury?
 - (b) How about acutely after your injury?
6. In what ways do you act toward your body?
 - (a) How about before your injury?
 - (b) How about acutely after your injury?
7. Tell me about how people in your life (partners, family, and friends) affect your body image.
8. What matters the most in regard to body image for someone who has an SCI?
9. What do you consider to be the ideal body?
10. What do you think having a negative body image means?
11. Is there anything else that you feel is important when it comes to body image, especially for someone with an SCI?

SCI: spinal cord injury.

A common method used in grounded theory research is in-depth interviews. For the purpose of this project, interviews were semi-structured allowing the flow to be determined by the respondent and the researcher to explore unexpected material as it arose (Patton, 2002). The main questions were developed using the definition of body image, whereby the four components (i.e. thoughts, feelings, perceptions, and behaviors) were broken down into questions (e.g. how do you see your body?). In addition, questions were designed to probe about before, acutely after, and longer term after injury to explore changes in body image over time. Interviews were conducted iteratively, meaning each interview was conducted, transcribed, and coded before the next interview commenced. Furthermore, each new interview was coded within the context of the previous interviews using the constant comparative method (Charmaz, 2006). Interviews took place on the university campus in a private office or at the participant's own home. Prior to the interview, participants provided written informed consent and completed general demographic information. The one-on-one interviews ranged from 60 minutes to 2 hours in length and participants were offered a break midway through the interview. Then, a few weeks later, two participants (Caroline and Danny) were recruited to do a follow-up interview to elaborate on specific concepts. Follow-up interviews lasted about 60 minutes. All interviews were audio recorded for transcription purposes, and participants were compensated CAD\$20.

To ensure authenticity, credibility, and trustworthiness of the data, we followed Lincoln and Guba's (1986) recommendations. Member checking was used to ensure proper terminology, sensitivity, and definitions of concepts were interpreted properly. Within 1 week of each interview, participants were provided by email a summary of their interview to review whereby they could correct or supplement

information. To maintain authenticity, participants' own words are displayed as quotations in the results. As recommended by Patton (2002), a tool to maintain the trustworthiness of the data is to have independent coders analyze the interviews. The first and second authors (K.A.B. and K.L.G., respectively) were the independent coders for this study. At the time of the study, K.A.B. was a female master's student who had completed graduate and undergraduate courses in qualitative research. K.L.G. was a female faculty member with extensive research experience in the area of body image and self-presentational concerns across the lifespan using both qualitative and quantitative designs. The two authors coded the first interview independently and came to an interrater agreement of 90 percent. Then, for the 10 percent disagreement, a discussion about codes lasted until consensus was made on all concepts. Since interrater agreement was high, the authors agreed to meet for the fifth and ninth interviews independently, and K.A.B. coded the other interviews herself. Interrater agreement remained at 90 percent for the fifth and ninth interviews. Triangulation of data (telephone interviews, one-on-one interviews, follow-up interviews, and field notes) was used to converge information, and multiple researchers worked together to apply their different perspectives to strengthen concepts (Carpenter and Suto, 2008). The researchers agreed that saturation was reached on all major categories as no new insights for the major categories occurred in later interviews (Charmaz, 2006).

Data analysis

In grounded theory methodology, data collection and analysis are done simultaneously. One step of analysis was transcription of the interviews (converting oral conversation into written text) done verbatim immediately

after each interview. Nonverbal information (e.g. silence and emotional cues), collected in field notes during the interviews, was embedded into the transcripts. Analysis of grounded theory involves coding and organizing data. Charmaz (2006) describes three main coding processes: initial coding, focused coding, and axial coding. Initial coding is the first coding stage involving examining differences and similarities between events, actions, and interactions. Focused coding is the next step of analysis and is more directed, selective, and conceptual than in initial coding and is completed iteratively by constantly comparing data with data, an integral component of grounded theory analysis (Corbin and Strauss, 2008). According to Charmaz (2006), it is important to keep a memo of information throughout the analysis to organize conceptual understandings, analytic examinations, and to record thoughts, questions, and relationships between interviews. Axial coding relates categories to subcategories, outlines the boundaries of a category, and reassembles the data from initial coding to give coherence to the emerging analysis (Charmaz, 2006).

Results

Participants discussed the perceptual, cognitive, affective, and behavioral aspects of their body image and described them all as influenced by their injury. In fact, a broad spectrum of body image experiences was reported among the participants (ranging from very negative to very positive) as well as self-presentational experiences. Generally, it was easier for participants to discuss negative body image experiences. Therefore, for the purposes of this article, findings are focused mainly on negative body image experiences and how self-presentation emerged as an important and related factor. The following main categories were found: appearance, weight concerns, negative functional aspects, body disconnection, body nostalgia, hygiene and incontinence, and self-presentation.

Category 1: appearance

Appearance emerged as the core category of body image experiences. Appearance was the most frequently and saliently discussed aspect of body image for participants and therefore seemed to represent body image experiences since this category was mentioned by eight participants. The following subcategories emerged within appearance: negative appearance features and their wheelchair.

Negative appearance features. Seven participants found it easy to list negative physical aspects of their body. The most frequently discussed negative features that were a direct result of spinal cord injury were the legs and abdominal region. For Rebecca, she described her injury to directly affect every aspect of her body image. For example, she said,

It's [her injury] directly affected every single inch of my perception of my body, how I think about it, how I act towards it, how I feel about it, it's affected every inch because like I said before looks definitely meant something to me.

She described being very attractive before her injury (close to the Western ideal); however, since her injury, she described trying to "salvage" her appearance. Unfortunately, she explained that most aspects of her appearance had changed for the worst, such as her back (due to rod placements eliminating her feminine curvature), abdomen, legs, buttocks, and skin (due to rashes and pressure sores).

Almost every participant described feeling insecure about his or her abdomen due to a loss of abdominal musculature. Most of the women also discussed frustration with the fact their arms have become bulkier with muscle since their injury due to constant wheeling and transferring. This frustration stemmed from not being in line with the thin ideal as bulk is not found to be socially desirable in women. However, for the men, they were mostly satisfied with the size of their arms and shoulders because they were larger, consistent with the cultural male ideal.

Wheelchair. Four participants considered their wheelchair to be an important aspect of their appearance. For example, this was the case for Mark as his wheelchair made a huge difference in how he felt about his appearance. He said,

I've been feeling a lot better I've got a different chair ... the chair you're in makes a huge difference in how you look at yourself because in my old chair I use to be slouching and now I look more upright and slimmer and it makes such a difference.

Rebecca explained a wheelchair to be her "ride," similar to that of a car. She said, "looking at other people's wheelchairs and it's almost like someone else's ride you know, but ultimately it's to make your body image look better." For Will, he mentioned the importance of being in a manual wheelchair as opposed to an electric wheelchair. He said, "my occupational therapist wanted to fit me for a power chair and I'm like 'well I don't really want to be in a power chair I want to use a manual chair because it looks cool.'"

Category 2: weight concerns

Weight concerns were also discussed as central to body image experiences among four participants. Weight concerns emerged as a distinct category because weight was not only related to appearance aspects but also other aspects of the body such as health, function, independence, accessibility, and hygiene. For Lizzy, weight concerns were a major issue to her body image. She was very preoccupied with her weight; for example, she said, "I mean, I'm aware that I've gained weight ... it's something that I need to work on" and "I know I need to lose weight ...". For Lizzy, weight was a topic that emerged frequently. Mark described

most of his thoughts, feelings, and perceptions about his body to be centered on weight. He said,

Well like I said I was really fit beforehand and I enjoyed the way I looked before. Now, I can feel like I am overweight now, still kind of working on that. That is an ongoing thought. Basically, that is basically it. I feel like I am constantly overweight.

Some participants described a fear of gaining weight because that inevitably resulted in getting a larger wheelchair which exacerbates issues of accessibility.

Category 3: negative functional aspects

A category that emerged which seemed particularly important for five participants was negative functional aspects. This category is unique to someone who has a spinal cord injury because of the distinct physical changes that occur to the body resulting in some loss in function. In fact, Rebecca described her body to be “luggage” since her injury. Functionally, she described having to drag her legs around when she transfers. She said,

It's [her body] my luggage now. When I'm having to transfer in and out of wheelchairs I see my legs it's not what my legs look like it's more “ok I gotta drag my legs over” they are more like luggage.

Negative functional experiences were particularly salient acutely after injury. For example, Mark said, “It was just scary. Everything like nothing moves nothing is moving my fingers were dead like couldn't move my hands I was upset it's because it's just upsetting really.”

Category 4: body nostalgia

Six participants described deep nostalgic thoughts about their body from before their injury. Primarily, they were nostalgic about their appearance, but some also mentioned being nostalgic about their body function. One way participants demonstrated body nostalgia was by glorifying their body before their injury. Many participants considered their body pre-injury to be very close to the Western cultural ideal. In fact, when asked what their ideal body is now, many suggested their body before their injury, such as Will, who said, “No, I was the ideal.” Samantha also believed herself to be close to the ideal before her injury. She explained,

Well I am 5'9 so I'm quite tall and I was probably 120 pounds, I was thin and tall and blonde and you know could turn a few heads kind of thing ... I guess I was pretty hot haha.

Rebecca conveyed the most nostalgic thoughts about her body from before her injury. She too explained her appearance to be very close to the ideal and found herself

constantly thinking back to how her body used to appear. For example, she ruminates about certain body features, saying,

I was so upset because I was actually very, very happy with my chest size before my accident and was I guess one of those features that I really, really liked beforehand and now I'm kinda, I still again I'm always looking back and I'm like “I wish they were the size they were.”

Category 5: body disconnection

This category emerged as seven participants seemingly had a dualistic or disconnected view of their body. Body disconnection was explained as physical, emotional, or perceptual. Physically, participants discussed not wanting to touch their lower body. Emotionally and perceptually, participants described the body to be a machine, would feel desensitized to private aspects of their body, or would never want to see their lower body in a full-length mirror. The most profound disconnection was described between the mobile and immobile aspects of the body. For example, Mark blatantly said that body image did not apply to his legs because they are immobile. He said, “I can't really say much about my lower body because it's immobile. It's not like I can be like ‘look at my legs’ so like body image doesn't really apply to my lower body.” Samantha also demonstrated a disconnection with her body, she said,

It's funny because I often think about my body I think about two separate bodies ... sometimes when I refer to my legs it's almost like a different part of my body or like my stomach or the parts that I can't move or don't work properly I almost think of as like a separate entity.

Another form of disconnection was depicted by participants who referred to their body as a machine, as if the body was a separate entity from the mind. For example, Larry often used a car analogy to explain a disconnection he felt to his least functional leg:

... it's [his body] a machine and if it's not working or if I have a useless part on the machine I don't need it then why drag it around I look at it as though you know roof rack on a car if you aren't using a roof rack and it's not doing anything for you if it's not helping you out or anything then get rid of it. Why keep it?

Larry also had an emotional disconnection to his legs, particularly the leg that has the least function. He suggested to his doctor that he amputate his left leg, since he has no function or emotional connection to that leg.

Category 6: hygiene and incontinence

One important aspect of body image was feeling clean. Therefore, one threat to body image was incontinence,

which was described by four participants in this study. Incontinence was also linked to self-presentation as smelling of urine or feces were reminders of not being “normal.” Two subcategories were found for hygiene and incontinence: aesthetic reasons and health reasons.

Aesthetic reasons. Aesthetically, it was important for two participants to smell clean as there was an inherent fear of smelling, particularly of urine. This was described as a very salient body image concern, particularly acutely after injury when participants had very little control of their body function. For example, when Rebecca was asked about the most important aspect of body image immediately after an injury, she said, “Feeling clean! Feeling clean because ultimately after a spinal cord injury, you can’t shower and you can’t do anything except bed baths ...” Rebecca explained being able to have a shower again as one of the best times after her injury in terms of body image. She said, “‘oh my gosh I get to feel clean!’ Like how I would normally feel before the accident, like you know an actual shower ...”

Danny was the only participant who used a leg bag to contain his urine. He explained his leg bag to negatively influence his body image. He was preoccupied with thoughts of whether it was visible to other people or if it made him smell unclean. For example, he said,

You have to make sure that the leg bag doesn’t get too full, you have to watch how much you have to drink ... you have to be careful with what you wear so that it doesn’t kink anything in your tubing ... you know the odour ... sometimes your tube gets caught up on your leg and then that makes a mess all over your pants and then you stink like piss and then it’s like “oh well now that I stink like piss I don’t want to be here anymore!” and embarrass myself.

For Danny, his leg bag was a constant reminder that he had a disability which was not socially desirable to him, and therefore, he would engage in self-presentational tactics (e.g. the use of clothing) to conceal his leg bag. This experience left him feeling worse about his body image and also perpetuated greater self-presentational concerns.

Health reasons. Two participants had a need to be clean in order to prevent infections. If participants did not maintain a high level of hygiene, secondary complications such as urinary tract infections were exacerbated. The constant susceptibility to infection was also a psychological reminder of not being “normal,” which caused negative body image as well as greater self-presentational concerns. Therefore, participants were motivated to remain hygienic. Samantha explained proper hygiene to be a fundamental aspect of taking care of the body after a spinal cord injury. She said,

I think it’s important that people take care of themselves like you I mean this sounds so basic but that you shower and you do proper grooming techniques and that you do take care of

yourself because I play wheelchair basketball and there are a few people on our team who do not it’s so unfortunate I mean you could look so much better or smell better you have to take care of yourself and all your body issues and stuff like that is really important to maintain that sense of well-being and being clean is all important.

Category 7: self-presentation

Seven participants explained having some sort of self-presentational concerns or engaging in tactics to maintain a certain image to others that was important (e.g. being perceived as “normal” or independent). It is interesting that this category emerged when no interview questions were designed to probe about self-presentation. In fact, self-presentation is a distinct concept from body image (as it involves concerns over the impressions held by others). Two subcategories were found to emerge: physical attractiveness and attributive tactics.

Physical attractiveness. Seven participants, including all five women, were preoccupied with ways to enhance physical features to be perceived as more attractive by the opposite sex. Some methods used by participants included being fashion conscious, wearing make-up and jewelry, and using clothing to hide or accentuate certain features and were all consistent with the Western cultural ideal. Samantha even went to the extreme of getting cosmetic enhancement (breast augmentation) since her injury. She described this method as a way to compensate for the physical disability, and had she not been injured, she may not have considered seeking this type of surgery.

Rebecca described always being preoccupied with her physical attractiveness. She described feeling much less confident since her injury and more self-conscious about how she appears to others. For example, she said, “I’m again more conscious about ‘oh my gosh are my feet together or not together or sloppy or do I look a little bit more disabled than I am?’ Because being disabled, there are different degrees of being disabled.” One strategy to look “less disabled” was to improve her appearance. She described being much more focused on her appearance since her injury and being even more attentive to hygiene than before her injury.

The women in this study discussed having an inherent fear immediately after their injury of not being found attractive by men. Samantha explained the adjustment period to be a time filled with many negative thoughts. She said, “I was like ‘what man would ever want me, how am I going to get a boyfriend’ you know, ‘I am all disfigured.’” Clothing was the main method described to enhance or conceal certain features, but some more dramatic methods (e.g. breast augmentation and liposuction) were also discussed.

Attributive tactics. Seven participants in this study reported distinct self-presentational tactics used to help manage

stigma associated with having a disability. Star and Lizzy explained receiving inappropriate and degrading comments about their use of a wheelchair which negatively influenced their own perceptions and attitudes about their body. Danny explained a deep concern with how other “able-body” people have negative perceptions toward people who use a wheelchair. Rebecca explained trying to give the impression that she is confident, although she explained truly having very low self-confidence stemming from the internalization of stigma. She said,

People see and notice the wheelchair right away and would always point out the wheelchair ... So I portray myself as, as someone ... I don't slump, chest out, I hold my hands a certain way that I know looks flattering as opposed to doing something that is not very attractive and so I make sure I cross my legs whenever I can.

Rebecca said that it is important to her to be perceived as physically active. Samantha shared a similar concern. She did not want to be perceived as lazy so she would remain active by exercising and being involved in sports; however, Caroline described sometimes not wanting to leave the house in fear of public humiliation from incontinence. She discussed many efforts to camouflage that she had a bladder or bowel accident. She described always having extra clothes and pads with her in case of an accident in an effort to prevent other people from knowing. Sometimes she would avoid leaving the house all together in fear she might be incontinent.

Five participants discussed a strong motivation or need to be perceived as “normal” by others. Rebecca was very consciously aware of how her body appeared to others and would engage in tactics to appear more “normal.” Star described a need to “blend in the crowd” and a need to normalize. She said,

I mean we come from this dominant culture of able-bodiedness so you know we even as people with disabilities try to normalize as much as possible so I know even with this you know we are girls with spinal cord injury sometimes we don't like to associate too much with each other because we want to be more normal ...

This statement made by Star is particularly compelling. It seems that the cultural standard to look “normal” can be so powerful that some people with a physical disability may minimize association with others who have a disability for fear it will threaten their desire to be perceived as “normal.”

Discussion

The purpose of this study was to broadly explore body-related experiences in men and women with spinal cord injury. In this study, participants described their injuries to directly affect all dimensions (perceptual, cognitive, affective, and behavioral) of their body image. Moreover,

participants in this study had quite a range of body image experiences. One notable trend was that with greater years post-injury, participants were able to experience more positive body image experiences (e.g. Bailey et al., 2015). Self-presentation was also found to be an important and related factor. Therefore, body image and self-presentation played a significant role in the experiences of having a spinal cord injury for participants in this study. Interestingly, appearance emerged as the core category for participants. This was due to most participants predominately discussing appearance aspects of their body image. However, interestingly, there was clear ambivalence between what participants believed should be important to their body image (i.e. function) and what they actually spent time discussing (i.e. appearance).

One particularly compelling finding was the need for participants to be viewed as “normal.” “Normalizing” the body through strategies of covering up visible disabilities and enhancing other aspects creates a self-concept that is not solely based on one's disability. In efforts to preserve a favorable image, people with spinal cord injury have been found to focus on efforts to appear as similar to the able-bodied community as possible (Dewis, 1989). This need can be understood as a drive for normalcy, similar to the drive for thinness or drive for muscularity found in non-spinal cord injured samples. Participants who shared a drive for normalcy demonstrated having a cognitive schema which associates being “normal” with socially desirable characteristics (e.g. power, social status, and desirability). This then led some participants to engage in certain tactics (e.g. withdrawing or engaging in physical activity and concealment of body attributes), in pursuit of attaining the ideal image of being “normal.” In fact, many participants explained an able body or the body they had before their injury to be their ideal—an undoubtedly impossible goal and therefore problematic to body image experiences as this discrepancy may lead to increased body dissatisfaction and decreased body esteem as has been found in college samples (e.g. Bessenoff and Snow, 2006).

Overall, participants would regularly engage in self-presentational tactics to preserve their social image which was inevitably related to their body image. One participant went to the extreme of having reconstructive surgery in order to be found more attractive. In fact, self-presentational motives are the primary reasons women give for seeking breast augmentation (Birtchnell et al., 1990). Other than the typical risks associated with surgery, breast augmentation carries the additional risk of obscuring breast tissue on standard mammograms, thereby reducing the early detection of breast cancer (Miglioretti et al., 2004). Women with spinal cord injury may feel more compelled to receive cosmetic surgery in order to compensate for their disability putting them at a greater health risk. Women and men must contend with Westernized gender roles and body ideals that are constantly imposed

on them. For women with a disability, this has been described as a “double impediment” (Henderson et al., 1994) as they face discrimination from being a woman as well as having a disability.

Body image and self-presentation have been documented to have both positive and negative influences on health behavior (e.g. Grogan, 2006; Martin et al., 2000). Implications of these concerns may extend to hospital, rehabilitation, and exercise settings to improve care administered to people with spinal cord injury. For example, the exercise context may be a place of particular body image and self-presentational concerns among clients as it is a very physique salient environment. This concern may be problematic since physical activity has been well documented as a significant contributor to health and quality of life for people with spinal cord injury (e.g. Hicks et al., 2003), and therefore, involvement in activity is critical. A concrete recommendation for medical and rehabilitation staff would be to encourage and provide social support. Since staff have the potential to be a positive influence on body image thereby encouraging health-enhancing behaviors, seminar series should be held to educate medical professionals on the importance of social support for people with spinal cord injury.

This study used a modified grounded theory methodology as a starting point for other researchers to further explore this area of research. Participants provided rich descriptions of their body image and self-presentational experiences allowing the findings from this study to be transferred to other people who also have spinal cord injury. Nonetheless, there are some important limitations of this study that should be addressed. First, there was a lack of diversity among participants as everyone identified as being Caucasian; therefore, other ethnicities are not represented. Furthermore, all participants in this study used a manual wheelchair, and most participants were highly physically active with high functionality and independence levels. Therefore, these findings may not represent individuals who are sedentary, with less mobility, and use electric wheelchairs.

Future research should continue to investigate body-related experiences in individuals with other physical disabilities. This study opens avenues in research to explore quantitatively how body image and self-presentational concerns or tactics affect exercise adherence, health, and well-being or quality of life for those living with a spinal cord injury. Mixed methods designs may help tap into both the negative and positive experiences following an acquired disability to help tease out how individuals with disability may adjust more positively after injury, thereby living a higher quality of life.

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